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ABSTRACT

The paper examines select state plans of deinstitutionalization, mandated by federal regulations. The current status and projected needs of programs and services for mentally retarded people are reviewed in particular to find out the states' guidelines in implementing the deinstitutionalization efforts. The review covers community residential living arrangements, community programs in training/employment, and community education. Areas of further research and training are suggested. It is concluded that the priority services mandated by P.L. 95-602 in the areas of alternative community living arrangement, case management, and nonvocational social development services are particularly designed to meet the needs of mentally retarded persons on an individual basis, to insure their adjustment to community life styles. A list of references, a schema of alternative living arrangements in the deinstitutionalization process, and tables with statistical data conclude the document. (Author/SB)

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DEINSTITUTIONALIZATION OF MENTALLY RETARDED PEOPLE: KEY TRENDS AND PATTERNS

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DEINSTITUTIONALIZATION OF MENTALLY RETARDED PEOPLE: KEY TRENDS AND PATTERNS[1]

Abstract

This paper examines select state plans on deinstitutionalization, mandated by the federal regulations. The current status and projected needs of programs and services for mentally retarded people are particularly reviewed, to find out the states' guidelines in implementing the deinstitutionalization efforts. The review includes community residential living arrangements, community programs in training/employment, and community education. The areas of further research and training are suggested to augment the deinstitutionalization process.

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[1]Adapted from a paper presented by the author at the 104th Annual Meeting of the American Association on Mental Deficiency, San Francisco, California, May 11-16, 1980.

DEINSTITUTIONALIZATION OF MENTALLY RETARDED PEOPLE: KEY TRENDS AND PATTERNS

The key concept in the deinstitutionalization movement is the provision of the "least restrictive alternatives" to the handicapped individual according to his potential to allow him for his fullest growth. The federal enabling act (Public Law 91-517, as amended by Public Law 94-103 and Public Law 95-602) stipulates that the deinstitutionalization plan should be designed "(A) to eliminate inappropriate placement in institutions of persons with developmental disabilities, and (B) to improve the quality of care and the state of surroundings of persons for whom institutional care is appropriate." An institution orientation usually implies regimentation in procedures and processes; invariable approach to treatment, training and habilitation services; depersonalization and disregard of human rights and dignity; and lack of a "total environment for life experiences according to developmental needs." In contrast, deinstitutionalization generally refers to one or more of the following goals: establishment of the community-based service system to prevent unnecessary or inappropriate placement in institutions; personalization of mentally retarded people based on individual differences, and socialization for participation in community-based programs and services; preparation of the community for social support of mentally retarded residents released for community placement; and improving all aspects of institutional programs to make the environs more humane and near to normality. This paper is intended to examine select state plans on deinstitutionalization in light of the above broadly stated considerations,

and to find out the states' guidelines in implementing the federal mandate. Based on the review of the state plans, the areas of further research on deinstitutionalization are also suggested.

Developmental Disabilities, and Federal Regulations

The developmental disabilities concept postulates comprehensive, lifelong, supportive services for developmentally disabled persons. The federal regulations mandate all states to submit an overall state plan to the Secretary of Health, Education and Welfare. The Developmental Disabilities Assistance and Bill of Rights Act (Public Law 95-602) is designed to provide funds and resources for the state to plan and implement a broad, comprehensive service network. The Act also provides assurance for the protection of rights of developmentally disabled individuals, and for provision of services for optimal personal development.

Public Law 95-602 also identifies and defines four priority service areas, and mandates that the extent and scope of priority services being provided, or to be provided, be assessed and described each year. These are: (1) case management services, (2) child development services, (3) alternative community living arrangement services, and (4) nonvocational social-developmental services. Public Law 95-602, however, limits its funding to no more than two priority areas each year.

Procedure

The study is based on selected state plans, mandated by the federal regulations. In all 23 states were selected, and requested to send their overall plans along with other related material. The states which were considered progressive in the deinstitutionalization movement were approached, keeping in view their geographic distribution in order to secure a representative sample. Of the 23 states addressed, fifteen sent their plans, two reported that they had not developed any plans so far, and six did not respond.

Programs and Services: Current Status and Projected Needs

A survey of the literature shows that there has been a trend toward deinstitutionalization of mentally retarded persons residing in a variety of state long-term care facilities within approximately the last two decades. The resident population generally reached its peak in 1967. From that time onward, there has been a steady and continued overall decline as resources for community placement were developed. The early emphasis on depopulation or diversion of institutional residents has now shifted to provision of comprehensive services to facilitate a "normalizing" movement from the institutional status to relative independence. Congruent with the underlying philosophy is the developmental approach to deinstitutionalization, which takes into account the stages of individual development, continuity of comprehensive services, and progression from total dependence toward independence.

Community Residential Living Arrangements

The legal mandate of the federal government does not require abolition of all institutions. As a matter of fact, institutionalization is the most appropriate residential alternative for those individuals who are severely disabled and who tend to require the most sophisticated forms of clinical, educational and residential services. Such interdisciplinary services are often available only in the state institution today. The reformed institutional setting under the federal program governing intermediate care facilities for the mentally retarded (ICF-MR) includes skilled nursing facilities, large ICF-MR facilities, and small ICF-MR facilities (with 15 or fewer beds). It is, however, clear that such institutional reform is part of the overall deinstitutionalization plan, which promotes community living with the goal of relative independence under the "most-enhancing" conditions.

Research studies on community adjustment of mentally retarded persons discharged from institutions have so far produced conflicting results. Based on an extensive review of literature, Crawford (1979) concluded that "deinstitutionalization is not living upto expectation." On the other hand, there is a groundswell of support from other researchers (Freedman, 1976; Gardner, 1977; Scheerenberger & Felsenthal, 1977; Burish, 1979; Polivka, & others, 1979), whose studies provide evidence of adequate community adjustment by a large number of mentally retarded persons. These findings are further corroborated by the phenomenal growth of community residence for retarded individuals during the past several years (Ebert, 1979; Bruininks, Hauber, & Kudla, 1980).

The national goal, set up by the President in 1971, was to return by 1981 one-third of the nation's institutionalized mentally retarded persons to the community. Commensurate with this national direction, all the state plans under study selected "Alternative Community Living Arrangement Services" as the target priority area. From a review of these documents, a design of community residential facilities emerges which is presented in Figure 1.

Insert Figure 1 about here

It is reported that the national average of institutional rate in mental retardation services is 71.14 persons per 100,000 population (Alabama State Department of Mental Health, 1979, p. 2). The large, multipurpose state institutions, and the intermediate care facilities for the mentally retarded (large and small) and the skilled nursing facilities - the first two phases in the continuum of domiciliary services - are intended to provide long term institutional care. The last two phases - community based residential settingsand home placement - are designed for community integration leading toward independence.

In order to determine the least restrictive residential environment for institutional clients, a match is generally sought between the specific criteria of the placement setting and the following client characteristics: age, functional level, physical ability, and social competency. The individual's social behavior, however, receives the primary consideration in determining potential placement. As explained in the Maryland state plan, "if one held the age factor as a constant, predictions related to community residential adaptability might be regarded in terms of the interaction among three components: 1) social behavior; 2) functioning level; and 3) state of health and level of ambulation." While social behavior is considered as the most significant factor in placement, ambulation and health, and functional level are regarded as having equal weights. Asocial/anti-social behavior, non-ambulatory health conditions, and functional deficit negatively influence placement in a community residence.

An attempt has been made to compile deinstitutionalization data from the state plans under study. The figures could be extrapolated in some form from the bulk of the data available in thirteen state plans, and should, therefore, be used as rough estimates. No such information could be extracted from the remaining two state plans. A summary of the data is presented in Table 1.

Insert Table 1 about here

A continued reduction in the number of institutional residents is contingent on the development of community-based services. It, however, appears from the above data that the deinstitutionalization efforts will begin to level off during the next two to three years. In some states, the trend could slightly reverse as the overall state population increases and as the methods of identifying new "cases" improve.

Community Programs
in Training/Employment

Some of the state plans have reported their prevalence estimates of mental retardation. These range from 1.52% to 3% of the overall state population. Based on a study conducted by Northern Indiana DD Service planner, John Hagan, Indiana State plan has provided an account for differential occurrence of mental retardation by age and severity level. These estimates, presented in Table 2, provide a broad profile of mentally retarded clients, and may be of some interest to other planners. Once the 1980 federal census is complete, more current and definite data will be available, and the projections will be more accurate for program planning and service delivery.

Insert Table 2 about here

Training

The federal regulations governing the intermediate care facilities for the mentally retarded subdivide levels of functional ability into degrees of supervision required. In the state plans these criteria were generally used to characterize the present resident population for purposes of deinstitutionalization. This is a shift from the old medical model to "functional deficit approach" to delivery of comprehensive services. The latter model represents "a remedial approach to strengthen specific skills." There is, however, some controversy as to whether normative developmental behaviors should be used as educational objectives for severely/profoundly handicapped children. Based on an exhaustive review of research studies, Switzky and others (1979) have remarked that "additional non-normative behavioral sequences may have to be added to allow severely and profoundly multihandicapped children to acquire a skill."

An integrated approach to program planning, which takes into account the acquisition of developmental skills and the remediation of specific deficit skills, is exemplified in the California State plan (California State Department of

Health, 1976). Based on a multifactor analytic approach, the DD planners identified from the state institutions 6,012 individuals who might be adequately served in community programs if the appropriate continuum of services were developed. These individuals were sorted into 12 naturally occurring clusters on the basis of their functioning on 59 items in the four areas of: 1) Self-sufficiency, 2) Motor coordination, 3) Communication, and 4) Self-control. The clusters were arranged so that the cluster composed of the most disabled individuals was Cluster 1 and the least disabled was Cluster 12. Contiguous clusters are most similar to each other. Programmatic needs of each cluster are considered in determining the types of placement facilities, so that the residents can be divided into small groups and individualized attention can be directed toward the developmental and functional needs of each resident.

With the shift of treatment and services from large, centralized institutional settings to community living arrangements, issues have been raised pertaining to manpower planning and staff training. A statistical report from a Massachusetts agency (Residential Care Facilities Report, 1976, cited in Ebert, 1979) reveals that more than 60% of community residence personnel are non-professional. ICF-MR regulations mandate that a staff training program should be developed to include orientation, in-service training, and supervisory and management training for new employees as necessary. Such training is to be provided to staff for other community facilities as well. In order to improve the quality of direct service, ICF-MR regulations further require higher staff to resident ratios than in the past. Training/ retraining programs can be initiated under these regulations.

Employment

Job success for mentally retarded persons is closely linked up with suitable community placement. A consensus could be drawn from an extensive review of followup studies, conducted by Eagle (1967), that favorable conditions in the community-based living situation lead to successful job placement. Other researchers (Mitra, 1976; Holmes, 1979) support this point of view.

Sheltered workshops occupy a key position in the training/employment continuum, just as group homes are a viable part of the residential continuum for mentally retarded people. A model continuum of training/employment would include the following programs in terms of progression: 1) Work-study programs in public schools, 2) Work-activity training centers for adults, 3) Sheltered workshops, and 4) Competitive employment. It is reasonable to expect that, if the continuum of comprehensive services from childhood to adulthood is properly provided, "lifetime earnings of the retarded adult, particularly those with an IQ of 50 or over, would exceed the amount of money that the taxpayer would have to pay in order to maintain this retarded individual within a residential center" (Conley, 1973, cited in Maryland Department of Health and Mental Hygiene, 1976-1990).

Community Education

Deinstitutionalization involves a social change, and altering community structures. Community support is, therefore, imperative to make the system work. In order to achieve this end, a vigorous program of public education is built into some of the state plans. The basic issues addressed in the program relate to the protection of civil rights of developmentally disabled persons. These include right to education, eliminating discrimination in employment opportunities, affirmative hiring policies, confidentiality of personal records, and provision of transportation, education, and health services. Citizen advocacy groups are primarily

concerned with these problems, and look to providers of services for redress. Public information efforts are also directed to ameliorating negative public attitudes as well as disseminating information about resources and services available to disabled citizenry. Besides publications and media presentations used for augmenting public awareness, some states conduct workshops and seminars about their computerized service programs. Two such programs are: New Jersey's Statewide Computerized Referral-Information Program (SCRIP), and Minnesota's Patient-Oriented Information System (POIS).

One problem of great import is community reaction to the siting of residential facilities for mentally handicapped people. "Zoning and other land use planning efforts focus on excluding the 'non-conforming' land uses which threaten neighborhood stability and the maintenance of quality of residential life" (Wolpert, 1978). However, the research study conducted by Wolpert does "not support the assertion of group home impact on neighborhood property values," nor on "property turnover rates." Two other studies reviewed in this report also produced more or less similar results. Much work need be done to communicate vital information of this nature to the group home neighborhood, so that community cooperation may be enlisted to stop "exclusionary zoning practices." In spite of the zoning controversies, group homes have so far played an effective role in the deinstitutionalization movement.

Conclusion

Deinstitutionalization plans provide a blueprint of comprehensive, life-long services for the retarded individual leading him toward a more normal life, maximizing his human qualities. The continuum of services in most cases is still at a conceptual plane to be translated into an operable model.

Unanticipated adjustment difficulties, referred to as "transition shock," might be experienced by mentally retarded people in the course of relocation to community (Coffman, & Harris, Jr., 1980). Even intra-institutional

transfer might pose a serious problem for a profoundly retarded individual to the total adjustment process (Cleland & Swartz, 1969, cited in Rago, 1976). The implications of transitional adjustments warrant due consideration in all cases of relocation.

The incidence of "recidivism" from group homes and other community living facilities, that is, readmission to institution is also of some concern to planners and administrators. Although the recidivism rate from group homes is reported to be about 10% (Sitkei, 1980), a mechanism for follow-along services provided for in the priority service area of case management should be set up to monitor the results of all isntitutional discharges.

Policies of non-discrimination because of handicaps, and accessibility to all programs and services will increase the visibility of all handicapped individuals including the retarded. Such exposure, augmented by vigorous campaigning of professional advocacy groups, will engender community awareness and enhance community acceptance of handicapped individuals.

Studies suggest that the direct experience of retarded persons and their adaptation to community life should be investigated, and support services must be found within the community itself (Browning & Rhoades, 1979; Browning & Bostwick, 1979). Some of the areas of concern voiced in the literature (Aninger, Growick, & Bolinsky, 1979) are: 1) employment, 2) sex, 3) marriage, 4) nutrition, and 5) loneliness. These are the areas which require further study. The problem of staff "burn-out" is also a question to be considered by administrators.

In conclusion, the priority services mandated by Public Law 95-602 in the areas of alternative community living arrangement, case management, and non-vocational social development services are particularly designed to meet the needs of mentally retarded persons on an individual basis, to insure their adjustment to community life style. Follow-along services, if properly implemented, will fill the long-felt service gap in the continuum of care.

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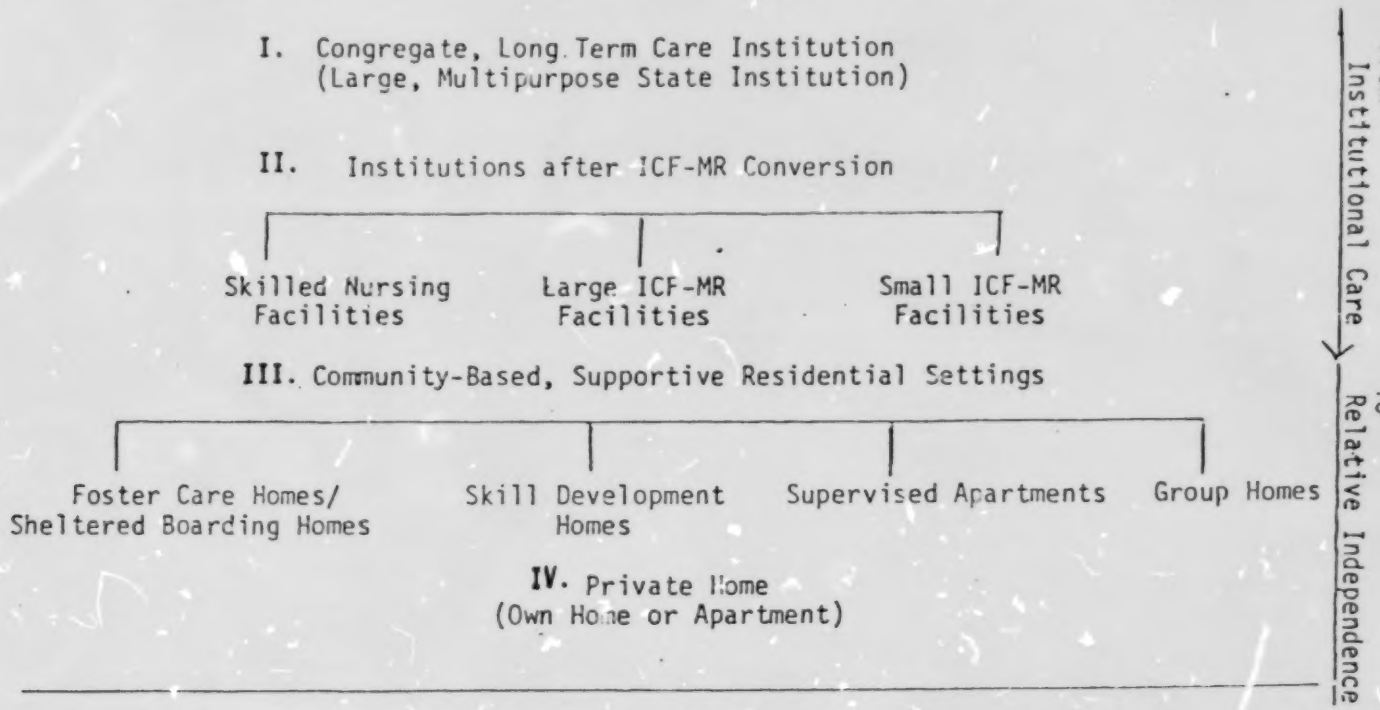
Figure 1

A Schema of Alternative Living Arrangements
in the Deinstitutionalization Process



*Note. (a) Foster Care Homes/Sheltered Boarding - for children and adults requiring room, board, and some personal care.

(b) Skill Development Homes - for children and adults who may be helped through a home training regimen for self-care skills.

(c) Supervised Apartments - for mildly or moderately retarded adults eligible for competitive employment or sheltered employment.

(d) Group Homes - for children and adults of all retardation levels who are not severely medically involved.

(e) Small Group ICF-MR's - with 15 or fewer beds for severely and profoundly retarded children and adults whose medical or physical handicaps would preclude foster placement.

*Adapted from: New Jersey Developmental Disabilities Council, 1980, pp. 261-264.

Table 1

Summary of Deinstitutionalization Data

State	Institutional Population			Total Number for Whom Institutionalization Is Appropriate
	Base Figure	Estimate I	Estimate II	
Alabama	1,678 (1979)	1,642 (1980)	1,605 (1981)	1,569
Arkansas	3,472 (1980)	3,472 (1985)	—	—
California	6,202 (1975)	3,000 (1980)	3,000 (1985)	—
Florida	3,577 (1979-80)	3,255 (1980-81)	2,932 (1981-82)	—
Illinois	6,239 (1979)	3,641 (1985)	—	—
Indiana	2,389 (1979)	2,454 (1984)	—	—
Maryland	3,261 (1977)	2,254* (1985)	—	2,014
Michigan	7,957 (1973)	5,258 (Actual) (1979)	3,540 (1980-81)	—
Minnesota	3,256 (1976)	2,757 (Actual) (1977)	—	—
New Jersey	7,709 (1979-80)	7,389 (1980-81)	6,911 (1981-82)	4,280
New York	13,894 (1979-80)	11,459 (1980-81)	9,919 (1981-82)	—
Pennsylvania	7,674 (1977-78)	4,912 (1982-83)	3,381 (1987-88)	—
Virginia	5,628 (1972)	3,759 (Actual) (1979)	—	—

*Maryland projections incorporate the increase in total population of mentally retarded persons in the state, and the absorption into mental retardation facilities of 384 persons in mental health state residential centers.

Table 2

Percentages of Mentally Retarded Persons
by Age and Severity Level

Age Level	Level of Severity		
	Mild	Moderate	Severe
Preschool (0 - 4 yrs.)	.01596	.02202	.00202
School Age (5 - 18 yrs.)	.25995	.35702	.03300
Adult (over 18 yrs.)	.12394	.17103	.01502

Source: Indiana State Department of Mental Health, 1980, p. II-4.